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BMJ Open Health service needs and perspectives of remote forest communities in Papua New Guinea: study protocol for combined clinical and rapid anthropological assessments with parallel treatment of urgent cases

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ABSTRACT

Introduction Our project follows community requests for health service incorporation into conservation collaborations in the rainforests of Papua New Guinea (PNG). This protocol is for health needs assessments, our first step in coplanning medical provision in communities with no existing health data.

Methods and analysis The study includes clinical assessments and rapid anthropological assessment procedures (RAP) exploring the health needs and perspectives of partner communities in two areas, conducted over 6 weeks fieldwork. First, in Wanang village (population c.200), which is set in lowland rainforest. Second, in six communities (population c.3000) along an altitudinal transect up the highest mountain in PNG, Mount Wilhelm. Individual primary care assessments incorporate physical examinations and questioning (providing qualitative and quantitative data) while RAP includes focus groups, interviews and field observations (providing qualitative data). Given absence of in-community primary care, treatments are offered alongside research activity but will not form part of the study. Data are collected by a research fellow, primary care clinician and two PNG research technicians. After quantitative and qualitative analyses, we will report: ethnoclassifications of disease, causes, symptoms and perceived appropriate treatment; community rankings of disease importance and service needs; attitudes regarding health service provision; disease burdens and associations with altitudinal-related variables and cultural practices. To aid wider use study tools are in online supplemental file, and paper and ODK versions are available free from the corresponding author.

Ethics and dissemination Challenges include supporting informed consent in communities with low literacy and diverse cultures, moral duties to provide treatment

Strengths and limitations of this study

- Our research responds to community requests and does not target external disease priorities, potentially better supporting bottom-up service planning.
- The methodology enables rapid assessment of local health issues within cost-effective time frames.
- The mixed-method approach provides increased confidence in findings by triangulation of qualitative and quantitative data.
- Treating urgent cases is an immediate benefit to partner communities in advance of full provision of health services.
- Rapid assessment can overlook social nuance which may be picked up by slower ethnography, and its broad focus reduces capacity to report health burdens as accurately as single-disease focused research.

alongside research in medically underserved areas while minimising risks of therapeutic misconception and inappropriate inducement, and PNG research capacity building. Brighton and Sussex Medical School (UK), PNG Institute of Medical Research and PNG Medical Research Advisory Committee have approved the study. Dissemination will be via journals, village meetings and plain language summaries.

INTRODUCTION

The SURFACES project¹ aims to support and exemplify integrated approaches to human health and biodiversity conservation² in the rainforests of Papua New Guinea (PNG). Our

approach is framed by Planetary Health,³ which looks to safeguard both human health and the natural systems that underpin it.⁴ This protocol is for combined clinical and rapid anthropological assessments of health needs and perspectives, with parallel treatment of urgent cases. We are conducting these as the first step in codesigning health service incorporation into existing conservation collaborations. Here, we give study context and justify why combined clinical and rapid anthropological assessment is the most appropriate method to collect foundational data in our settings. We detail our methodology, and outline ethical issues involved. Study tools are available in online supplemental file to support wider use.

PNG's globally important forests are threatened by logging,^{5,6} and its health-related UN Sustainable Development Goal indicators are worse than all but two countries outside sub-Saharan Africa.⁷ Rates of maternal deaths are among the highest in the world.⁸ Today's landscape of health in PNG has been shaped by ecological, social and historical factors. For example, its populations are highly dispersed across topographically challenging tropical settings.⁶ As a result, tropical disease burdens are high and maintaining medical services is logistically difficult. This inherent geographical problem has been worsened by a colonial and postcolonial history in which medical resources concentrated in the newly constructed towns,⁹ and novel diseases arrived from more crowded countries.¹⁰ Thus, desire is often high for in-community health services, even in remote places. The experience of the Hagahai people in the forested fringe-highlands of Madang province is illustrative. The Hagahai had long defended their virtual isolation from outsiders, both New Guinean and colonial. Yet they actively relinquished it to obtain medical services, in a bid to save their population

from decimation by infectious diseases and pregnancy-related deaths. Cultural isolation had left them with only a sparse medicinal botany, which was insufficient for many endemic diseases, and provided little defence against the epidemics that had followed sporadic contact.¹¹ Against such backgrounds, rural and remote aid posts are the primary care interface for much of PNG's population. Unfortunately, they are often relatively neglected, unstaffed, unstocked and in many areas simply do not exist. In 2016, 40% of registered Aid Posts nationally were not operating (1217 of 3074).¹² This lack of community healthcare infrastructure is compounded by a tendency for in-bound global medical funding to give precedence to international disease targets, at a cost to PNG capacity to control other threats to health which may be local priorities.¹³

When the logging frontier reached Wanang (figure 1) in 2001 a coalition of clans chose to preserve 10 000 ha of forest as communities all around them allowed logging. Clan leaders reached out to a PNG land rights NGO, and through them legally declared a multiclan conservation agreement¹⁴ (Wanang conservation area, <http://baloun.entu.cas.cz/png/wanang/>) and formed a partnership with New Guinea Binatang Research Centre (BRC), University of Sussex (UoS), University of Minnesota and other international organisations. This has enabled them to protect their forest, while benefitting from both the ecosystem services it provides and additional development advantages accessed through the conservation collaboration. These have included a school, employment and training in research, conservation payments, local transportation and international travel.⁶ In 2016, leaders of the nine clans that form the Wanang conservation area, BRC staff and village school board members met to discuss the

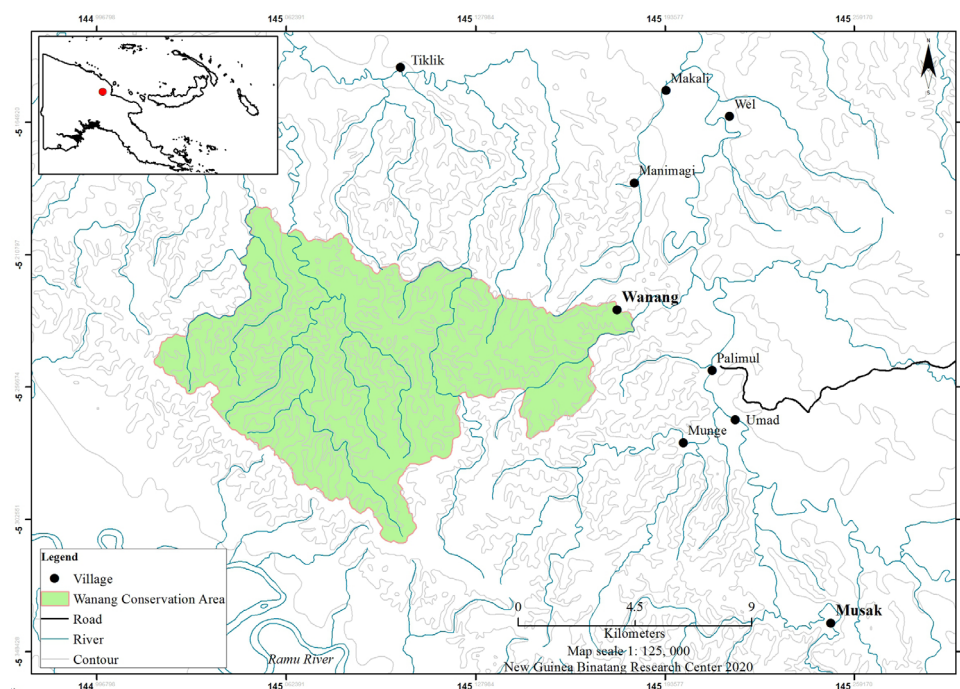


Figure 1 Wanang conservation area and Wanang village, Papua New Guinea.

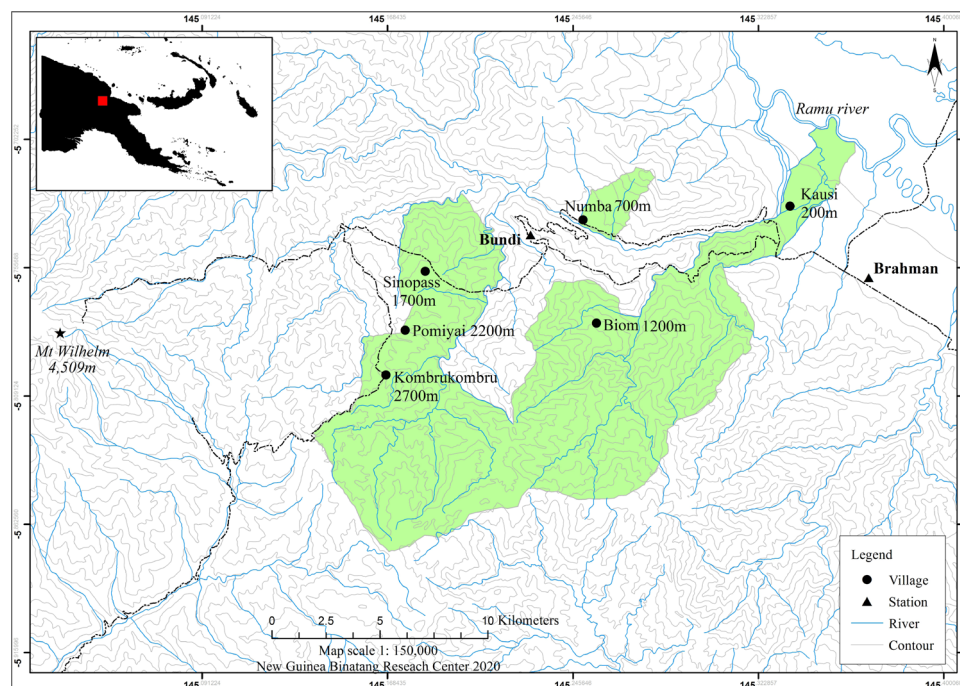


Figure 2 Mount Wilhelm research and conservation area, Papua New Guinea. Traditional landowners have together agreed to conserve the area shaded in green. Road access (dotted lines) to the marked settlements is seasonal and only possible by four-wheel drive vehicles. Given the expected timing of the health needs assessments team travel between the study populations on Mt Wilhelm is likely to be entirely by foot.

future of the project. Together they identified healthcare as ‘the main missing service at present’ to be developed as part of the collaboration in its next phase.¹⁵ One of the clan leaders present is someone who practises traditional healing and was a strong proponent of bringing biomedical primary care services to his community. At present, in the absence of an Aid Post, villagers travel c.80 km to either access medical care at a regional hospital or purchase drugs at a pharmacy.

At Mt. Wilhelm, PNGs highest mountain (figure 2), partner communities, BRC and UoS have established research stations along an altitudinal transect of rainforest 200–3700 m. Biodiversity surveys are informing site selection for protected areas and, inspired by the success at Wanang, clans have formed a similar collaboration, the Mount Wilhelm Research and Conservation Area (<http://baloun.entu.cas.cz/png/mtwilhelm/rainforest-transect>). Modern healthcare remains distant from most settlements along the transect, villagers have stated some aid posts are up to a 6-hour journey by foot.¹⁶ As at Wanang clan landowners along the transect met with BRC and requested healthcare be included in the collaboration.

Following these community decisions, we are carrying out needs assessments to determine clinical and community priorities. We have to collect clinical data ourselves as there is no pre-existing government health statistics for either area, and no prior medical studies covered either population. The only pre-existing medical records are individual’s health books, which only a minority of community members own and keep with them in

their houses. We will consult these during assessments. However, they are often inconsistent, as they are required to access hospital care and so are swapped between people as care passports.¹⁷ We need to collect data on perspectives regarding health services (existing and desired) as no previous work has been carried out in these communities, and such understanding is necessary to coplan future provision.

Methodological choice

Our needs assessments are designed to maximise community participation in health priority setting and service planning, and actively consider local environmental and cultural disease contexts across heterogeneous societies and physical environments. They also provide an opportunity to study relationships between disease and environmental and cultural factors in communities with little prior health research. We have chosen to carry out combined clinical and rapid anthropological assessments, a mixed-methods approach which allows us to carry out needs assessments that collect both qualitative and quantitative data, at both individual and community levels, and then triangulate data.¹⁸

Rapid anthropological assessment procedures (RAP) is a suite of rapid data collection methods based on anthropological techniques and adapted for use with health programmes. Developed by UN University, it is especially useful in scoping where longer more rooted ethnographical approaches are impractical, and little to no health data exists.^{19 20} RAPs are qualitative assessments (usually 4–6 weeks) of local health conditions and needs, knowledge,

attitudes and practices. They usually include interviews with key informants, focus groups and field observations. Guides were produced in the 1980–1990s.^{19 21} RAP was designed to be carried out by multidisciplinary teams of outside mid-level researchers (such as masters graduates) and local research assistants.²²

One strength of RAP compared with more conventional epidemiological surveillance is that it enables participants to speak about health in their own voice, using local ethno-classifications of disease.¹⁹ This is helpful in our study areas as local research¹⁷ and investigator knowledge²³ suggests biomedical labelling and explanations of disease/treatment are not dominant, and are often held in parallel with traditional and/or recently introduced disease classifications. RAPs primary operational strengths are speed and the reduced staffing costs of mid-level researchers, but these are also responsible for its greatest limitations. First, its findings risk being decontextualised field observations simply used to drive interventions, as they inevitably lack the nuanced understanding of long term, truly ethnographic, and overtly theory framed work of ‘pukka anthropologists’.²⁴ For example, RAPs seek ethnoclassifications of disease, but as with their methodological twin ‘Rapid Rural Appraisals’ there is a risk researchers may listen, may collect, but still not necessarily understand how such categories are actually used in the local context.²⁵ Nevertheless, we feel the approach is appropriate and sufficient for the limited (primarily applied) purposes of our study, and we expect it to provide data to attract funding for more protracted, ethnographic work alongside service introduction. RAPs have often been designed for vertical health programmes (ie, HIV; malaria; guinea worm).²⁶ Yet when focus is preselected by outsiders, this can reduce the extent to which rapid approaches enable genuine bottom up planning.²⁵ Ours are broad community health assessments, so largely avoid this problem, but the cost of not having a predetermined focus is the risk that rapid research becomes shallower still.

We are conducting individual clinical assessments alongside RAP, as relying solely on community perspectives will provide insufficient data for ethnoclassifications to be translated into actionable disease targets. Triangulation of RAP outputs with clinical observations should give us a clearer picture. Clinical data can also be used as a baseline to support evaluation of future interventions. Finally, primary care discussions between clinician and patient can unearth insights that may not be volunteered in group settings or by key informants (who by political necessity are those with village power). Clinical questioning and examination will follow a primary care approach of assessing participant health by body system, but diagnostic certainty is limited by the extent of point-of-care and secondary care-based testing available for this study. Clinician involvement in data collection also enables treatment of urgent cases alongside research activity. This is an immediate benefit of the conservation collaborations in advance of full-scale incorporation of health services, and we hope this acts as a conservation incentive. However, our main reasons for providing

treatments are the ethical considerations discussed in the protocols concluding section.

To our knowledge no RAP-based study protocol has been published in the academic literature (online supplemental file). We suspect this is because RAP was developed before widespread protocol publishing became a norm, and its use has primarily been for applied purposes rather than publication-orientated academic research.^{22 26} In addition, many documents concerning RAP and related methodologies are predigital. Publication of our protocol may aid its wider adoption, with the addition of clinical assessment with a quantitative component and parallel medical treatments. To aid use, study tools are in online supplemental file, and questionnaire-style paper forms and coded Open Data Kit (ODK) versions are available from the corresponding author. All tools are free to use on the condition this paper is cited in output publications.

Aims

To build synergies (and avoid trade-offs) between conservation and healthcare delivery, and build the foundations for health interventions and interdisciplinary research studies with our partner communities, we are commencing SURFACES¹ with on-site needs assessments. Their overarching research question is: What are the health needs of BRC-UoS partner communities in the Wanang and Mount Wilhelm conservation areas?

In addition, we have the following subsidiary research questions:

- ▶ How do people in our partner communities classify diseases, describe their symptoms, and explain what causes them?
- ▶ How are these diseases treated, and by whom?
- ▶ At Mount Wilhelm, what associations are there between disease burden and altitudinally determined variables or observed/reported cultural practices?

METHODS AND ANALYSIS

Figure 3 illustrates our methodological approach. Clinical assessment consists of individual primary care assessments incorporating physical examinations and questioning, carried out by a primary care healthcare professional (PC-HCP) with relevant experience (eg, a general practitioner, tropical medicine nurse or a PNG Health Extension Officer). The RAP include focus groups, semistructured interviews and field observations. The PC-HCP give treatments and referrals as necessary, but these will not be included in the study.

Study personnel

AJS is principal investigator, JAC project clinical lead at UoS. Data collection will be managed in the field by JM (hereafter, the research fellow (RF)), with a team consisting of a PC-HCP, and two PNG Research Technicians (RTs, one male, one female) already employed by BRC. The RF has prior experience in PNG, and at least one RT will have worked in the communities previously and have focus group and interview skills. The RF will

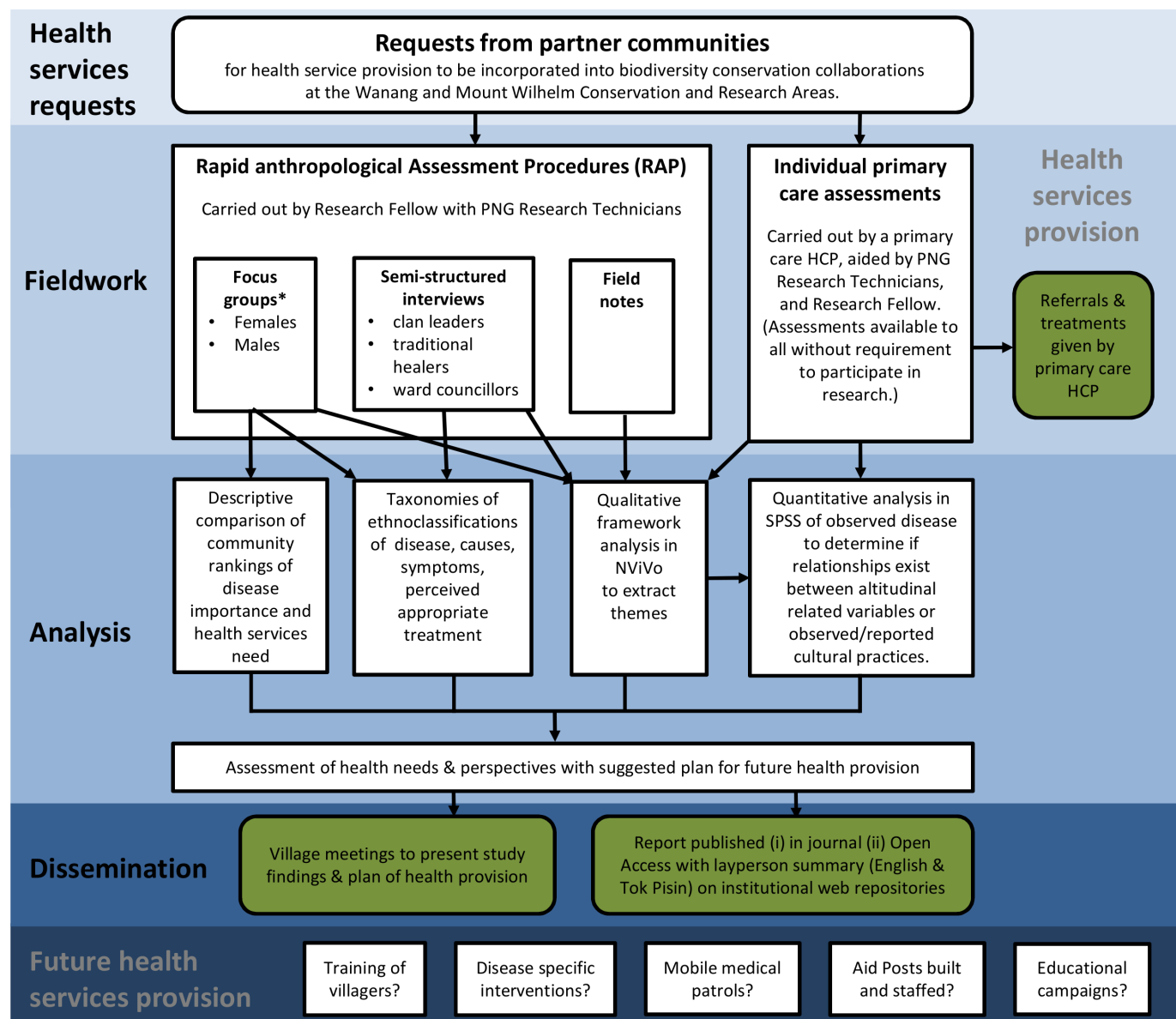


Figure 3 Methodological approach. Green boxes are outputs. If we provide training to villagers, it will be in line with needs determined in the assessments, but would likely consist of short courses in topics such as trauma care and evacuation, or self-management of skin diseases. *At Mount Wilhelm same-sex focus groups will be conducted, at Wanang these will be further divided by age group (18–39 years old, ≥40 years old). HCP, healthcare professional; PNG, Papua New Guinea.

provide further training (online supplemental file) and with RTs carry out the RAP. The PC-HCP will carry out individual primary care assessments, supported by the RTs and RF. The RF will conduct analysis informed by multidisciplinary reflection from coinvestigators and collaborators. Specifically, from anthropology (JF and HM), global health (MGH), PNG health research (ML, WP), mycology (JI), statistics (CJJ), ecology (FD, VN, MP, AJS), tropical dermatology (SLW), primary care (GC) and public health and epidemiology (JAC).

Study population

Wanang conservation area

Wanang (figure 1) is the only settlement within 10 000 ha of unlogged lowland rainforest in the Ramu River floodplains.²⁷ In 2016, it consisted of 89 females and 100 males:

<10 years, 66 individuals; 10–19 years, 51; 20–30 years, 32; 31–40 years, 20; 41–50 years, 6; ≥51 years, 17 (data provided by MK), and it also hosts a school for the wider area. Its nine clans subsist primarily through horticulture and foraging, living in traditional structures. They share their forest with a huge variety of plants and animals, 536 plant species from 50 ha alone.⁶ Wanang has no aid post or access to primary care and the nearest hospital is 80 km along seasonal logging roads.

Mount Wilhelm research and conservation area

Mt. Wilhelm (figure 2) is one of the seven most plant species-rich sites worldwide, hosts half of PNG's bird species, and nearly a third of its butterfly species.⁶ Based on 2017 data provided by collaborator EB, c.3000 people live at seven points in the area, which consists of a 41 km

Table 1 Study cohort and justification of participant numbers and composition

Site and method	Participant targets and justification
Wanang conservation area	
Individual semistructured interviews	≥11 interviews, so (1) all nine clan leaders offered an interview, as well as (2) someone who carries out traditional medical practices and (3) a ward councillor.
Focus groups	16–32 people in total, four focus groups (4–8 participants each, all ≥18 years), (1) females 18–39 years, (2) males 18–39 years, (3) females ≥40 years, (4) males ≥40 years. There are less than 20 people >50 years in the settlement.
Individual primary care assessments	≥200 (all ages). We expect to recruit most of the community, which will provide (1) broad quantitative data on clinical impression of health status and individual-level medical history, and (2) opportunity for a basic primary care assessment for all clan members at Wanang.
Mount Wilhelm research and conservation area	
Individual semistructured interviews	7–21. Up to 21 to enable (1) leaders of each clan hosting one of the seven research stations to be offered an interview, and (2) if present someone who carries out traditional medical practices at each site and (3) ward councillors.
Focus groups	56–112 in total, two focus groups at each of 7 altitudinal points (4–8 participants each, all ≥18 years), (1) females, (2) males. While it would be ideal to carry out age-based focus groups, it would be impractical to attempt to do so at each of the seven research stations.
Individual primary care assessments	10% (300 people, all ages) from the seven settlements, with no more than 20% of the total coming from any one. Using 2017 household-level data, we aim to recruit a representative sample as per age and sex in each village, though recruitment will be highly dependent on participants seeking health assessment. This level of recruitment is (1) logistically possible in the 3 weeks the team intend to spend on the transect, (2) should provide sufficient data for exploratory statistical modelling of disease incidence and demographic/cultural and altitudinal variables and (3) provide sufficient data for recommendations for future health service provision.

long, 5 km wide transect. A further c.2000 live in a settlement at the top of the transect, but are not included in this assessment due to study constraints and their existing access to some health resources. Horticulture remains the main basis of subsistence, and settlements are dispersed. A dirt road, only driveable by 4×4 and very often impassable, runs the length of the transect. There are no in-community health services, and aid posts are up to 6 hours walk away. Research stations, mainly consisting of temporary structures, are positioned up the mountain at regular intervals.

Inclusion and exclusion criteria

For semistructured interviews and focus groups, we are including anyone who lives at a research site ≥18 years with capacity to give informed consent, and fits the criteria in table 1. For individual primary care assessments, we are including anyone who lives at a research site (1) ≥18 years with capacity to give informed consent or (2) <18 years with informed consent of their accompanying guardian (normally a parent). In some communities, exact ages may not have been documented and PNG staff will advise on how best to ascertain age. For example, major events are sometimes used to estimate age in PNG, such as for older people how old they think they were when PNG became Independent, or when they first heard/saw aeroplanes or flooding of local major rivers.

Study design

Data collection is expected to take 5–6 weeks in total. Data were collected at Wanang for 9 days commencing 17 July 2018. After this piloting we reflected on the process

and tools, and made minor alterations in preparation for the more logistically complex data collection up Mt. Wilhelm planned for November 2020 to January 2021 (dependent on COVID-19-related restrictions). We aim for analysis to be complete 31 March 2021. To support an understanding of context and enable informal field observations data collectors live in the study settlements or nearby community managed research stations.²⁸

Recruitment and participation timelines

RTs first recruit known clan leaders for interviews, who identify other key informants. This is followed by focus groups and individual primary care assessments (c.25 per day). The process will be especially compressed up Mt. Wilhelm to enable visits to seven sites (timeline and recruitment documentation, online supplemental file). In less logistically challenging settings where greater time is available, it may be advisable to carry out focus groups and interviews prior to primary care assessments. This may reduce the risk of influencing participants to 'want' more of what is offered during the primary care assessments, as opposed to identifying what is of most importance to the community. However, they should still immediately precede individual primary care assessments to enable true time-bound comparisons between the medical needs stated by communities and those observed by clinicians. In addition, team clinicians should still be ready to provide emergency treatment at arrival in communities. If demand to participate in focus groups is greater than logistically possible, purposeful recruitment will reflect known demographics (further

detailed in table 1). A prioritisation system will be used if demand for individual primary care assessments is greater than logistically possible: (1) those with an illness they/their parent believe to be serious, (2) those with an illness they/their parent believe to be not serious, (3) those perceived (by themselves or their parent) to not have an illness.

Study procedures

Rapid anthropological assessment procedures

In each settlement, we will first interview clan leaders, ward councillors (locally elected representatives to local-level governments, committees which vary in the extent to which they exist off-paper) and (where present) traditional healers. We will thus collect the particular perspectives of these groups, whose influence can facilitate or block interventions. Interviewing clan leaders before wider data collection is also politically expedient if one wants to carry out research in these small communities, and is especially important where research targets social groups who may not always have a public voice (eg, young women). Engaging those who practise traditional healing in coplanning is important as they have experience of treating people in their communities. In addition, building health systems without their support might risk catalysing social division and undermining the long-term sustainability of healthcare. We are vigilant of this potential risk, though in the local region there is no strong competition between traditional healers and biomedicine, which typically exist in parallel. In the Madang area, traditional remedies tend to address presumed spiritual/social causes of illnesses (sorcery, spirits, relationships), while biomedicine is often seen as useful but purely symptomatic (not causal) treatment.^{17 23} We will endeavour through ethnographical observation to determine the relationships between these three sets of important actors (clan leaders, ward councillors, traditional healers), though the rapid nature of the method can be expected to only provide relatively limited insights.

In focus groups, the nominal group technique²⁹ will be used to frame discussion. Individual participants will be asked what the most important community health problems are and which services should be prioritised. The group will then discuss these answers, working together to rank top fives.³⁰ Community ascribed disease ethno-classifications may order discussion, where these arise. Once top five priorities are identified, community understanding of health problems, causes, symptoms and perceived appropriate treatment will be discussed. The RF and RTs will take brief field notes throughout the fieldwork, writing up expanded notes each evening to capture contextual information and facilitate reflection. To enable greater disclosure by informants, interviews and focus groups will be carried out by researchers of the same sex as participants,²⁸ and focus groups held separately by sex (and where logistically possible, age).

Individual primary care assessments

Medical history will be taken by RTs and/or RF using a questionnaire (online supplemental file). This will be followed by clinical interview and examination by the PC-HCP, with assistance from RTs functioning as male/female chaperones. The PC-HCP will undertake only non-intimate examinations unless there is both participant request and clinical need. If the PC-HCP suspects someone is suffering from Malaria a point-of-care test will be done (online supplemental file).

Treatments alongside the research

The PC-HCP will carry a targeted formulary and supplies such as splints and dressings (online supplemental file), taking responsibility for treatment conducted in line with PNG guidelines. Cases requiring further resources will be referred via existing in-country pathways. Treatments will not be analysed as part of the research.

COVID-19

For most of 2020 COVID-19 cases have been relatively low in PNG, but community transmission is now underway in some areas. The cumulative number of cases nationally is now 419, including four deaths (27 August 2020).³¹ The study will follow the COVID-19 operating guidelines of the PNG Institute for Medical Research (IMR). Coauthor WP is its national director, and coauthor ML is the head of its Vector-borne Diseases Unit (which is based in the same province as the study populations). In response to the rapidly evolving nature of the pandemic IMR is adapting and changing its institutional guidelines constantly. At present (August 2020) they include: in-country research staff will not travel between provinces and only continue to work when rates of COVID-19 are low or absent from their province; social distancing will be practiced in all research settings and the number of field staff in vehicles limited; in general facemasks are to be worn at all times at work or in public places (but see below) and sanitisers will be available; staff returning from provinces that report cases of COVID-19 will be quarantined and tested by RT-PCR as per the WHO protocol; COVID-19 awareness messages will be disseminated in communities being worked in. IMRs policy is that these general rules have to be adapted to what is practical on the ground in each locality. For instance, wearing masks and PPE at all times in communities' may frighten the population or make them hostile to researchers. At present, it is planned research staff will only wear masks during clinical examinations or treatments (as social distancing is not possible), and that these and all other research activities (focus groups, etc) will be carried out under tarpshelters mostly open at the sides to enable ventilation. All activities (including recommendations/responses) will be reviewed fortnightly by operational managers and senior management. In line with PNG government law any medical research staff coming into PNG will need to have had a negative COVID-19 test within a 7-day period prior to arrival, and will then self-isolate in a government

approved hotel for 7 or 14 days (depending on origin). In the event of encountering suspected COVID-19 cases during the study, samples will be collected and tested by IMR which is leading the RT-PCR testing for SARS-CoV-2 across PNG. Any tests conducted and any cases detected will be immediately reported to the COVID-19 Task Forces at national government and provincial levels, who will arrange response.

Data collection, processing and security measures

At Wanang, individual primary care assessment data were collected on paper forms which were subsequently adapted for collection on tablets for Mt. Wilhelm, using a tablet-server-based Open Data Kit system (<http://opendatakit.lshrm.ac.uk>). Given absence of in-community electrical sources these are powered from 20,000mAh powerbanks, charged by mobile 24W Outdoor Solar panels (RavPower, San Jose), with back-up power from an Infinite Orbit 5V 1A Hand Crank (Texenergy, Alton). Semistructured interviews and focus group recordings are transcribed in Tok Pisin, then translated by RTs. Personal information is retained/shared in anonymised form, but personal treatment information is not shared across co-investigators (Co-Is). All personal data entered into devices will be indexed by personal identifier, but no names entered. A separate (paper form) code book linking participant names and identifiers enables (1) linking data collected from individuals who participate in

both this and subsequent fieldwork planned to be carried out within twelve months, (2) evidence linking informed consent with participation and where required treatment. In the field this will be held by the PC-HCP, afterwards by the clinical lead. Personal data will be accessible during fieldwork to the RF, PC-HCP and RTs, subsequently to the RF, PC-HCP, and clinical lead. Information on treatments given and referrals will be included in a letter given to anyone who receives treatment, or is recommended to travel to health services. Further data curation details in online supplemental file.

Analysis

Qualitative and quantitative analysis will be conducted as per [figure 3](#), using NVivo (QSR International, Melbourne), and SPSS Statistics 25 (IBM). For quantitative analysis, variables will be summarised descriptively overall and by settlement. If disease rates are sufficient, multivariate regression techniques will model associations of demographic/cultural (and on Mt. Wilhelm, altitudinal) factors with each disease.

Rapid anthropological assessment procedures

Qualitative framework analysis will be carried out to extract themes from interviews, focus groups and field notes. Perspectives of community members in focus groups/interviews (on disease, causes, symptoms and perceived appropriate treatment) will be presented as taxonomies

CAUSE	Mother				Food		Tooth eruption	Fallen fontanel Fallen stomach	Evil eye	Stomach worms	Cold enters stomach	Disentery		
	Physical activity	Hot		Emotional	Bad food	Excess Does not eat on time	Quality							
		Hot foods	Pregnancy										Anger Sadness Fright	
SYMPTOMS All types have watery and frequent stools				Very dangerous	Flatulence, feeling of fullness			Tooth eruption	Green with mucus	Sunken fontanel vomiting, green in color	Fever	Worms	White in color	Blood in stools, "urgency"; color is red or black
TREATMENT	Not breastfeeding when hot	Mother changes diet	Breastfeeding stops	Home, drugstore, injectionist, witch, spiritist	Home, folk curer			None	Folk curer	Folk curer	Drugstore, home, folk curer	Folk curer	Folk curer	Home, drugstore, health post

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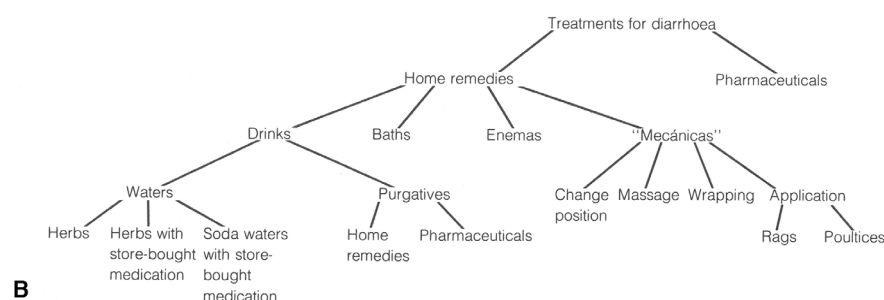


Figure 4 Examples of RAP generated ethnoclassifications/taxonomies. (A) Taxonomy of diarrhoea, (B) taxonomy of treatments for diarrhoea.¹⁹ Copyright retained by the UCLA Latin American Institute, who have granted permission to reproduce. RAP, rapid anthropological assessment procedures.

(figure 4). Community rankings of disease importance and health service needs will be compared between sites and sub-populations, and reported descriptively. Disease rankings from Mt. Wilhelm will be analysed statistically to determine if relationships exist with altitudinal-related variables and observed/reported cultural practices.

Individual primary care assessments

Medical histories and examination results will be reported descriptively, attitudes regarding health and service provision analysed qualitatively (as above). Individual primary care assessment data from Mt. Wilhelm will be analysed statistically to determine if relationships exist with altitudinal related variables (eg, respiratory conditions and indoor fires at higher elevations, increased malaria at lower elevations) or observed/reported cultural practices. Our study is not focused on particular disease targets in advance, but is a broad health assessment across highly heterogeneous terrain and cultures. It, thus, makes sense to plan the full analysis based on clinical data actually collected, rather than in expectation of what may be. Once all data are collected, we will develop a full analysis plan. This will be written prior to analysis to reduce risk of bias.

Patient and public involvement

This protocol was developed following community requests that healthcare be incorporated into existing collaborations. Thus, we are carrying out the assessments to determine clinical and community priorities as part of coplanning service introduction. PNG staff from the region were involved in design. Key informants were consulted to determine how this coplanning should be conducted. This included someone who practices traditional healing in one of the communities. However, given literacy levels in partner communities its members were not generally invited to contribute to writing or editing this protocol, with the exception of coauthor JP. Clan members are involved in recruitment (through identification of key informants and addressing community meetings) and advise on research conduct and burden. Health committees will be established subsequent to assessments and verbal report scripts and plain language summaries read to them to determine clarity, and adapted as needed prior to dissemination.

ETHICS AND DISSEMINATION

Approach to informed consent

Our partner communities are diverse, with multiple languages and cultures. For this reason, the PNG RTs will undertake recruitment and judge: how to ascertain age; who may be unsuitable to interview; where best and how to examine in a culturally sensitive manner; how best to respond if participants become distressed. To ensure informed consent verbal explanations will be given, including reading out provided copies of participant information sheets and consent forms (online supplemental file). Individuals will be given time to ask questions before signing consent. If they cannot read

and/or write, an independent witness will ensure participants understand the research, signing and filling in the consent form on their behalf. We expect most potential participants will understand either spoken Tok Pisin or English. For those who only speak local clan languages (most likely a small minority), RTs will provide translation or arrange through key informants in the community. Informed consent will be taken by RTs who have training according to in-country requirements, and will be given further training by the RF. Participants will be told they may withdraw at any time, and remove their data until the assessment report is written up. They will be given a cut-off before which they can telephone a named fluent speaker in Tok Pisin at BRC. They in turn will email the name to the RF, who will remove them from the database. Those <18years will only participate with signed consent of an accompanying guardian (normally a parent). When a child has an individual primary care assessment, a same-sex chaperone will be present (a family member or RT). The age at which this is appropriate is expected to differ between cultures. BRC and IMR staff will lead on this, and record decisions. In clan-based societies in PNG 'community consent' is required in addition to individual consent.³² This needs assessment follows community requests for health service provision. Nevertheless, clan leaders will be approached first at each site, and community meetings held to explain the study before individual recruitment. Based on in-country and local knowledge we are confident this method is suitable for our study populations, many of whom will already be familiar with it as result of previous experience with (non-medical) research. However, if this protocol is adopted elsewhere we would advise local concepts around the philosophy of consent are explored during project planning.

Providing urgent treatment alongside research

Our partner communities have no on-site primary care, and secondary care is remote from them. Given this, bringing clinicians into such communities but not providing treatment of urgent cases that present during the research would be unethical.³² We feel giving treatments from a minimal formulary and referrals as necessary is the most practical and ethical approach. The intention of these assessments are to provide a basis for future healthcare provision, and thus a benefit to partner communities and study participants. However, the study team is also extracting value from the community and its disease burden (ie, wages; data for academic publication, with implications for personal advancement). Treatment provision (alongside payment for accommodation, food and community access) goes some way to make the relationship more genuinely reciprocal from the start.

Providing treatment alongside research in settings such as our partner communities in PNG brings ethical challenges itself, as outlined previously by Co-Is ML, WP and colleagues.³² First is the 'risk of subordinating patient care in favour of scientific gain'. Our study is not a treatment evaluation, and this avoids most of the ethical hazards

associated with experimental design in medical research carried out in resource-limited settings. In addition, the need to treat acute emergencies will always take priority over research. The second challenge outlined by Laman *et al*⁸² relevant to our study is the ‘risk of therapeutic misconception and inappropriate treatment’. To reduce this risk experienced in-country researchers who understand local languages and cultures will be responsible for recruitment and taking consent. As desire for treatment and/or an individual primary care assessment may act as inappropriate inducement, they will make it clear that primary care assessments and treatments are available without requirement to participate in the research. To overcome these challenges overall, Laman *et al*⁸² emphasise the importance of oversight and involvement of ‘developing country ethics committees and institutions’ with local knowledge of practical and ethical issues. We submitted this protocol to two in-country boards (see the Ethical Permissions section) and welcomed amendments which made the design more culturally appropriate. PNG institutions have continued study oversight, including of any adverse events.

Capacity building for PNG research staff

Research carried out in PNG has not always centred development of in-country research capacity or given appropriate credit to PNG staff. For example, of non-medicinal biology papers which included ‘PNG’ in the title published 2003–2012, only 95 of 397 had at least one PNG author.⁶ All SURFACES PNG research staff will benefit from training in-country, and six will be brought to the UK and Czech Republic for targeted development (detailed in online supplemental file). PNG RTs and Co-Is will be involved in publications of the results as coauthors.

Safety considerations

There are potential hazards to both participants and researchers given the subjects the study covers, the offer of parallel treatments, and the social and ecological terrain it is being conducted in. These are outlined with mitigation measures in online supplemental file.

Ethical Permissions

This study and protocol was approved 26 June 2017 by the Research, Governance, and Ethics Committee of BSMS (UK) (ER/BSMS61566/1). It was subsequently submitted to the Institutional Review Board of IMR (PNG), receiving approval with minor amendments 12 October 2017. IMR subsequently submitted it to the PNG Medical Research Advisory Committee and received full approval 9 March 2018 (MRAC18.06).

Dissemination

Team members will give verbal summaries in public meetings in each village, and provide paper plain language summaries in English and Tok Pisin. Findings will be published in a journal, with the manuscript publicly accessible on BRC and UoS websites. The article will reference this protocol noting changes in method, and

include a filled-in reporting checklist based on criteria for appraising studies in health using RAP.²⁶

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